

## Chapter 3

# Parkinson's Disease: The Support Partner's Role in the Person with Parkinson's Levels of Wellness

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## Abstract

This chapter is about the support partners' trials as they endeavour to cope with daily life with a Parkinsonian partner. The philosophy underpinning the discussion is phenomenology, which is about being there and experiencing the journey of Parkinson's disease (PD). Support partners grapple with everyday life, not only to support their partner with PD, and the role they play as carers, but also their need to maintain their careers to ensure financial stability. Due to the changes in the condition, both mentally and physically, of the person with PD, support partners often feel a stranger has moved into the house. A lack of facial expression, inability to speak, and the risk of falls are common, but despite this they do not seek assistance from Parkinson's organisations, as they are "waiting until they get worse". However, without assistance, the frightening aspects of dealing with the stranger are experienced in isolation. Health professionals need to acknowledge that PD is a long-term condition with constant fluctuations in both mental and physical capability, therefore they should always include the support partner in any assessment processes. However, they should also remain mindful of the fact that support partners experience a sense of disloyalty when talking about their partner, or when they are contradicting statements made by the person with partner in their presence.

## Introduction

This chapter describes the journey of progressive nature of Parkinson's disease through the eyes (lenses) of support partners. The purpose of this chapter is to capture some of the experiences that support partners encounter in their day-to-day living with their Parkinsonian partner. The reason we are developing this chapter is that it is our experiences that few health professionals really understand the reality of being a support partner of someone with Parkinson's disease. Most health professionals (in our experience) try to provide answers, whereas support partners want health professionals to listen to and appreciate the support partners' realities. A Heideggerian phenomenology framework is used to analyse the experiences faced by the couples. In order to emphasise the support partners' perspectives, we open with short vignette of four support partners before providing an explanation of the theoretical underpinnings. Elements that we want to stress include facing the unknown of being the support partner of someone living with PD, the career and financial implications, as well as mindfulness of routine, watchfulness and work in the background to maintain independence for as long as possible. Some excerpts of the stories are shared to illustrate our points.

## The People

The examples given in this chapter are based on stories from four women. They are not unique stories, but

representative of many of the partners we have encountered. In order to maintain confidentiality, pseudonyms have been used when referring to individuals. Teresa was 50 year's old, Fionna and Yvonne 48, and Shona 60. None of them knew each other, but what Teresa, Shona, Fionna and Yvonne all have in common is that they are high level career executives, and these are the ages they were when their husbands were diagnosed with Parkinson's disease (PD). Teresa's husband, Nicholas, has had PD for over 16 years. He is 'well', fluctuating between stage III and Stage IV according to the Hoehn and Yahr [1] classification system. Nicholas is still able to mow the lawns, and maintain the garden. He also gets up to make the morning cup of tea, and reports that he regularly cooks the evening meal. While Nicholas is 'well', Teresa is troubled by the non-motor aspects of PD. Nicholas becomes anxious everytime Teresa leaves the house, and watches the clock, timing the moments until she returns from work. Fionna's husband has had PD for 10 years. He too, is fluctuating between stage III and IV, although there has been a deterioration in his level of wellness over the last three months. He makes a choice to either work in the garden or prepare the evening meal; he cannot manage both. He regularly has REM dreams; always having to fight off the invaders that enter the house. Therefore, Fionna regularly has disturbed sleep, but still needs to go to her work each day. Both work and home life are draining Fionna's resilience. Yvonne's husband is self-employed, therefore if he is not working,

he has no income. He frets about this and continues to work to the point of exhaustion. He cannot mentally cope with reducing his financial contribution to the household, despite the fact that Yvonne is able to financially support them both, as well as sponsoring their three high achieving adult children.

In contrast Shona's husband, Norman, who was diagnosed with PD 15 years ago, is more disabled, rating between stage IV and V on the Hoehn and Yahr scale. He uses a walker to mobilise around the house. He reports that he still mows the lawns, but Shona disputes this, and he has not brought her a cup of tea in bed for the last 12 months. He also claims that he is able to manage during the day, but fails to notice that Shona prepares a lunch for him, and needs to leave everything close at hand as he will not remember, for example, to drink fluids if the water bottle is not nearby. He spends the day reading, not noticing if housework needs to be done, and if he does put a load of washing on, he forgets to hang it out. On other days he cannot hang out the washing as unpredictable fluctuating changes means he is not safe to be picking up heavy pieces of clothing to place on the line. He also does not think to prepare the evening meal. While these are the vignettes of four women, they represent the stories of many support partners of those with PD.

## Theoretical Underpinnings

The framework for this chapter is underpinned by phenomenology. Phenomenology is grounded in an understanding that life is bound in tradition and common knowledge [2]. Questioning life does not occur in everyday experiences, which remain in the background; such questioning occurs when encountering the unexpected [2]. For example, when a significant event occurs, such as having a partner diagnosed with PD, those affected suddenly notice others with PD. While the diagnosis explains the strangeness of their partner's behaviour, the individual also notices others' reactions and interactions to the person with Parkinson's (PwP). They observe how people are disconcerted when communicating with the PwP by the mask-like facial expression, and therefore not receiving socially expected feedback. Support partners notice, as if for the first time, the norms of society towards someone who is 'different'. Heidegger referred to this as thrownness. When one is thrown, previous knowledge (or worldviews) evaporate. In this situation, all attention is now on the disease, and the implications that it can have.

In the early stages, most understanding of PD, is gained from internet searches, hearing or reading about famous people who have progressed in PD to become more disabled. When the PwP and the support partner see what PD can lead to, they are fearful of whether the future will unfold this way for them. Heidegger calls this fearsome, and goes on to explain previous perceptions shrink back

in the face of the fearsome and the individual wants to flee towards the familiar. In this case, it is not possible for the PwP to revert to 'not having PD', as there is no cure for PD; it can only be managed. This fearsome occurs because the fear has not yet eventuated; therefore, cannot be overcome [2]. Reflecting on the situation, and anticipated fear cause one to question life, and their worldview. These changes in worldview are made familiar and become known when the experience is shared with others; the circle of understanding [2]. For the support partner, it is almost as if an unwelcome stranger gradually takes over the person they once knew, a phenomenon recognised by others in the circle of understanding.

## Support Partner's Fearing and Facing the Unknown

As noted, PD is a progressive illness. The most widely used classification system for staging of PD was developed Hoehn and Yahr [1]. They defined criteria of five stages of disease: *Stage I* Unilateral involvement only with minimal or no functional impairment. *Stage II* Bilateral or midline involvement, without impairment of balance. *Stage III* First sign of impaired righting reflexes, manifested by unsteadiness when pivoting, or when pushed from standing equilibrium with the feet together and eyes closed. While the patient is capable of leading an independent life, employment, and activities may be compromised. *Stage IV* Fully developed, severely disabling disease; the patient is

still able to walk and stand unassisted but is markedly incapacitated. *Stage V*. The PwP is confinement to bed or wheelchair unless aided [1].

What is more recently recognised, and not noted in the Hoehn and Yahr scale, are the non-physical manifestations of PD, yet these are most troublesome and frightening [3] as the couple comes to terms with the unknown. For example, the most common non-motor manifestations include sleep disorders [4-7], depression, and apathy [6,8,9], anxiety and fretting that impact on continued social interaction [10], and less known, skin irritation [6,11]. The sleep disorders have only been recognised as a component of PD over the past 20 years [12], therefore not always recognised by health professionals. As reported

“One of the most puzzling aspects for me [in the early stages of the disease] was the fact that he would have terrible nightmares; imagining himself in a fight, or punching out at someone that had broken into the house. It was me he was punching. The nightmares would occur about 2am, and I was thrown out of a deep sleep into a bewildered state as I was under attack. I got punched, kicked, my fingers bent backwards, my arm twisted like a Chinese torture, to name a few injuries. Sometimes these would result in bruises, but not always. When I talked this over with friends [health professionals], it was suggested that I move into another bed in another room. Others dismissed the nightmares as the effect of medication – long before he was actually on any medication. The worst insult was when I was not believed.”

These non-motor effects of PD, on paper, are one dimensional, whereas, in reality, they generate multifaceted emotions and reactions. For example, apathy means that Fionna has to try and motivate her husband to attend activities outside of the house; activities he knows are beneficial, but he struggles to attend unless there is a direct purpose for him. Activities that include those that plateau PD, have no purpose to Fionna's husband. As noted earlier, Nicholas becomes very anxious and frets when Teresa is not at home. Both Fionna and Teresa are raked by guilt either for the gentle persuasion, as well as huge anxiety about their partners' capabilities when they leave the house.

Apathy goes hand-in-hand with depression [9]. Readers of this chapter need to bear in mind that, at the time of diagnosis, most PwP are living independently, but have a level of cognition that enables them to comprehend the future. That future adds to the depression. In the meantime, support partners recognise how important it is for their partners to engage in social activities, which distract from the depression, but grapple with how apathy impairs the PwP to engage in such activities. This struggle puts extra stress on the support partner. Coupled with this, it is our experience that many people do not seek assistance from Parkinson's organisations during the earlier stages of the disease; often "waiting until they get worse", resulting in the couple dealing with the effects of PD in isolation. The isolation can impose stress on the support partner who is trying to make sense of what is happening, and adopts

more of a role in running the household.

## Career Implications

As noted at the beginning of this chapter many of the PWP or their support partners are young, not having reached retirement age. Some PwP struggle to maintain their own employment, others no longer can remain in paid employment. It is reported that the changes in employment status, either forced into early retirement or modified roles in the place of employment, distresses the PwP [13]. Support partners' employment, in the meantime, can be also compromised. Fionna's husband was envious of her continued career success, Shona's husband inadvertently sabotages her continued work. Support partners are torn between careers and caring. For example, Shona is regularly torn between the two roles when Norman is not feeling well on the day she has a meeting that cannot be postponed, and if Nicholas has a restless night, the restlessness disturbs Teresa to the extent she is not at her best the next day. Any need for support partners to accompany their partner to the series of appointments that maintain the PwP degree of wellness results in the support partner needing an understanding employer, or team that enables flexibility. Situations such as these have potential implications for both the PwP and the support partner's career and financial situation.

Any change in professional employment is particularly relevant for women. Traditionally, on becoming mothers, many women place their career on hold for a period

of time [14,15], with some mothers assuming lower paid roles in order to adopt a primary role of motherhood [15]. On returning to the workforce, women may advance their career, gradually rising through the ranks to hold senior positions. It is our experience that the female PD support partners, now at the peak of their career, are again having to reconsider their options. Any work away from home or work that involves travel means that the support partner may be pressured to change employment in case they are required at a moment's notice. Others, whose work involves long hours or responsibilities, often need to compromise their plans or change the working conditions. The four women in the opening section of this chapter have all made changes in their career, either reducing the hours of work, relinquishing managerial or senior positions, or both.

The couples face financial implications if either the PwP or the support partner is midcareer [13,16]. Added to the financial implications of living on one wage, it is our experience that the PwP often becomes stressed when thinking about finances. As the disease progresses the support partner takes over more of the financial management [13]. However, taking over finances adds to the loss, or as reported "PD robbing me of something else." These issues are on-going and impact on the support partner with increasing degree of distress; distress that is compounded by the unpredictable nature of PD. In addition, support partners are often reframed in language as caregivers where once they were partners.

## Support Partner, or Caregivers

Many of the texts you read about PD focus on caregiver strain or burden. However, we want to emphasise that none of the four women named in the vignette, nor any of the partners of someone with PD are caregivers; they are first and foremost someone's wife or husband, and following discussions with these partners, they prefer to be known as support partners. By positioning them as support partners, the PwP is able to manage the condition with a degree of independency; the support partners' work is in the background. It is known that exercise, speech language therapy, and mental exercise, such as completing puzzles are all important to minimise the progressive decline in physical and mental status of the PwP [17].

The support partner notes whether the PwP is tired, adequately hydrated, not constipated, as well as getting a balance of physical and intellectual stimulation. In addition, the support partner watches the PwP's dietary intake, especially the level and timing of protein, which can interfere with the absorption of levodopa. However, the medications can also cause nausea, something else that the support partner is mindful of. Other common complications of PD are UTI, pneumonia and falls. Despite this, support partners report that it is hard work to keep the PwP enthusiastic about attending classes, or drinking an adequate amount of fluid, reporting that comments such as "Don't keep on at me" are hurtful and cause distress.

The work in the background can take its toll because the support partner is always mindful of maintaining the dignity of the PwP, but at times seeing themselves in a more parental not partnership role. For example,

“We have just come back from an overseas trip. I couldn't believe it...that...the anxiety for him at times. He thought he had run out of his drugs one night, and just felt lost. Just unbelievable; just totally overcome...Just dealing with that. It was out of the blue almost. We knew, I mean we had gone to the doctors had had heaps of drugs and so on. And when to step in because we [were travelling with a large tour group], so you did not want to...like you were mothering him or being the nagging wife, but you are quite protective at the same time.”

Although this example highlights anxiety as a consequence of being in an unfamiliar environment, the support partner works in the background every day to maintain the PwP's routine, and wellness. In 2015, an article was published [3] that focussed on the support partners' sorrow as they watch the PwP struggle on a daily basis. Most of the struggle is associated with the non-motor elements of PD. For example, a simple task of purchasing a few groceries can be a challenge if the PwP is in a strange supermarket, and is often unable to find the item when the packaging has changed. Added to what is now a difficult task, is the obstacle of asking someone for assistance, as the slurred speech is misunderstood as being intoxicated.

In our experience it is those elements that the support partner tries to minimise. As the disease progresses, the support partner adopts a more active role, and the PwP becomes their focus.

However, the support partner's role changes from husband or wife to caregiving, for this stranger who takes over the loved one. The stranger is the one that 'glares' at the support partner as PD affects their facial expression. Other disconcerting body language is grimace and unusual movements of the mouth. If non-verbal body language accounts for 55% of communication of the total message [18], the body language adds to a sense that PwP is a stranger, especially if PD has also robbed the PwP of their sense of humour and spontaneity.

## The Importance of Routine

The adage a change is as good as a holiday does not apply to a PwP, nor the support partner. In fact, a holiday can throw the PwP, as they struggle to cope with the change in routine. It is proposed that one strategy to manage the day-to-day of PD is living according to routine [19]. In addition, it is our finding that activities need to be planned on a daily basis so that the PwP can maintain independence for as long as possible and becomes more important as PD progresses. Living according to routine results in every activity needing to be planned, often for days ahead, yet the support partner also needs to be flexible if the PwP suddenly does not want to take part in the

planned activity. The support partner then needs to determine whether gentle persuasion is needed as the PwP may have lost confidence to participate in a social activity, or if they have some of the numerous complications of PD identified earlier.

It goes without saying that a loss of spontaneity can be tiring, especially if the support partner is on holiday from paid work, but the PwP cannot see past the routine of gym on Mondays and Tuesdays, swimming on Wednesdays, gardening on Thursdays, housework on Fridays, and suddenly “oh, the week’s leave has gone fast”. Other support partners have reported that their partner wants to accompany them to every activity; almost as if, once they are at home on leave the support partner loses the ability to plan independently. Therefore, employment is a legitimate reason for support partners to have time for themselves, but during vacation, they need a reason to leave the house, or have time alone. Alongside the need to maintain a routine identified, other strategies to manage PD are to be positive [19], but remaining positive can add additional pressure to the support partner to keep the person with PwP positive, especially amid the unpredictability of PD. For example,

“What were once simple tasks, such as collecting something from the supermarket are now complex activities that involve a trip to the toilet before leaving home, searching for a parking space that is close enough to the complex and wide enough to avoid freezing or faltering of

steps as he tries to negotiate his way around the car door, possibly another trip to the toilet on reaching the shopping complex, and finally searching for a trolley to lean on so that the he can negotiate the way around the supermarket aisles. All for the sake of a litre of milk.”

Overall, it needs to be recognized that PD is a family condition, not an individual condition. Therefore, it is our position that the way forward is to assess not only the PwP, but also the support partner.

## Health Professional and PD

When health professionals are assessing the person with PD, they need to ensure that they also assess the support partner, as the support partner will understand the reality of the physical and cognitive skill set; the PwP often exaggerating their ability. It is important, to be observing the support partner during this time to determine the congruency between both couples’ perceptions. However, the health professionals also need to remain cognisant of the fact that the support partner feels uncomfortable talking about the PwP in their presence; a sense of disloyalty. Health professionals need to acknowledge that PD is a long-term condition. As reported in some earlier research [3] when asked how is the PwP, a useful response is “He still has Parkinson’s. I do not know how to answer that question”.

Some research has been useful to determine the effects of PD on both of the couple [20]. Interview questions used in their research include examples such as

- Tell me about your usual day of caregiving
- How do you feel about your role as a caregiver?
- What are the barriers to your role?
- What sort of things would make caregiving easier for you?
- Tell me what you don't like about your caregiving role?
- Tell me what you like about your caregiving role?

The questions would be useful for both the support partner as well as the PwP. If, for example health professionals asked the PwP both what they did in a usual day, as well as what they thought the support partner did to assist them on a usual day, the health professional would be able to determine the level of insight that the PwP has into their own condition. This would also focus the role of the support partner, not caregiver; a role of varying degrees of the 24 hour/day management of the PwP; especially as the PwP will only remain 'well' because of the work in the background. Additional value would be added to the assessment if the health professional not only asked the how and what of each of the points proposed within this assessment, but also asked the why? For example "why do you not like [this aspect] of your caregiving role?" would not only alert the health professional to a change in PwP's

condition, but would also indicate whether there is a need for additional referral.

## Closure

As emphasized at the beginning of this chapter, the four identified, as support partners have a concerned interest in both their own partner who has PD, as well as shared interest in others in the group whom they had not met prior to the diagnosis of PD. Sadly, Norman's condition deteriorated to the extent that Shona could no longer manage him at home. Transferring him to long-term residential care has been a difficult experience for both Shona and Norman. Another of the PwP is having 'off' moments; moments when the medication is not as effective. This means the couple are on another roller-coaster of physical and emotional stress. Despite this, they need to continue their paid and unpaid employment. Health professionals need to remain mindful of the effects of PD on the couple as a whole, not merely the PwP. The support partner is in a state of thrownness endeavouring to maintain a sense of calm and soothing the unpredictable pathway of PD, and fluctuations that can vary on an hourly basis. Support partners need to financially support their partner, but may struggle to hold a career amid the chaotic state of that is not a daily occurrence. Health professionals need to remain mindful that the importance of routine for the PwP may add stress as the support partner tries to also instil some spontaneity into the couples' lives. A comprehensive assessment of both the PwP and support partner's will determine the issues that matter most to both of them.

## References

1. Hoehn M, Yahr M. Parkinsonism: Onset Progression and Mortality. *Neurology*. 1967; 17: 427-442.
2. Heidegger M. *Being and Time*. London: SCM Press Ltd. 1962.
3. Mercer C. The Impact of Non-Motor Manifestations of Parkinson's Disease on Partners: Understanding and Application of Chronic Sorrow Theory. *J Prim Health Care*. 2015; 7: 221-227.
4. Barnes J, Connelly V, Wiggs L, Boubert L, Maravic K. Sleep Patterns in Parkinson's Disease Patients with Visual Hallucinations. *Int J Neurosci*. 2010; 120: 564-569.
5. Menza M, DeFronzo Dobkin R, Marin HBK. Sleep Disturbances in Parkinson's Disease. *Mov Disord*. 2010; Supp1: S17-S22.
6. Snow B, Macdonald L. *Parkinson's: A Guide for the Newly Diagnosed*, 5th edn. Wellington: Parkinson's New Zealand. 2013.
7. Barber A, Dashtipour K. Sleep Disturbances in Parkinson's Disease with Emphasis on Rapid Eye Movement Sleep Behavior Disorder. *Int J Neurosci*. 2012; 122: 407-412.
8. Bosboom J, Stroffers D, Wolters E. Cognitive Dysfunction and Dementia in Parkinson's Disease. *J Neural Transm*. 2004; 111: 1303-1315.
9. Weintraub D, Stern M. Psychiatric Complications in Parkinson Disease. *Am J Geriatr Psychiatry*. 2005; 13: 844-851.
10. Wressle E, Engstrand C, Granérus A. Living with Parkinson's Disease: Elderly Patients' and Relatives' Perspective on Daily Living. *Aust Occup Ther J*. 2007; 54 :131-139.
11. Nolano M, Provitera V, Estraneo A, Selim M, Caporaso G, et al. Sensory Deficit in Parkinson's Disease: Evidence of a Cutaneous Denervation. *Brain*. 2008; 131: 1903-11.
12. Scaglione C, Vignatelli L, Plazzi G, Marchese R, Negrotti A, et al. Disorder (RBD) in Parkinson's Disease: REM Sleep Behaviour Disorder in Parkinson's Disease: A Questionnaire-Based Study. *Neurol Sci*. 2005; 25: 316-321.
13. Murphy R, Tubridy N, Kevelighan H, O'Riordan S. Parkinson's Disease: How is Employment Affected? *Ir J Med Sci*. 2013; 182: 415-419.
14. Kahn JR, García-Manglano J, Bianchi SM. The Motherhood Penalty at Midlife: Long-Term Effects of Children on Women's Careers. *J Marriage Fam*. 2014; 76: 56-72.
15. Staff J, Mortimer J. Explaining the Motherhood Wage Penalty During the Early Occupational Career. *Demography*. 2012; 49: 1-21.

16. McLaughlin D, Hasson F, Kernohan WG, Waldron M, McLaughlin M, et al. Living and Coping with Parkinson's Disease; Perceptions of Informal Carers. *Palliat Med.* 2010; 25: 177-182.
17. Šumec R, Filip R, Sheardová K, Bareš M. Psychological Benefits of Nonpharmacological Methods Aimed for Improving Balance in Parkinson's Disease: A Systematic Review. *Behav Neurol.* 2015; 2015: 1-15.
18. Doherty J. Parkinson's and relationships. [Online]. 2006. Available: [http://www.parkinsons.org.nz/sites/default/files/parkinsonian\\_archive/2009/Parkinsonsandrelationships.pdf](http://www.parkinsons.org.nz/sites/default/files/parkinsonian_archive/2009/Parkinsonsandrelationships.pdf). [Accessed 17 August 2016].
19. Haahr A, Kirkevold M, Hall E, Østergaard K. Living with Advanced Parkinson's Disease: A Constant Struggle with Unpredictability. *J AdvNurs.* 2011; 67: 408-417.
20. Tan S, Williams A, Morris M. Experiences of Carers of People with Parkinson's Disease in Singapore: A Qualitative Analysis. *J Clin Nurs.* 2012; 21: 2235-2246.